

## Facts about Michigan's Birth Defects Registry

- About 8,000 infants and toddlers with birth defects, chronic illnesses and developmental disabilities are identified each year.
- Michigan law requires hospitals and medical labs to report certain health conditions to the registry, which is maintained by the Michigan Department of Community Health.
- The registry is statewide and designed to help Michigan families obtain information, services and support.
- Information in the registry is confidential, and regulated by Michigan law. It can be used only to offer appropriate services to families, for prevention education, and for research on the causes of birth defects.
- Registry data may be used to track the rate of birth defects, measure public health efforts to reduce the number of birth defects, and help communities improve services.

**For more information, or to order additional copies of this pamphlet, please contact:**

The Birth Defects Follow-up Program  
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## Resources for Families of Infants and Toddlers with Special Health Needs



**Michigan Department of Community Health  
Birth Defects Follow-up Program**



After the birth or adoption of a child with special needs, parents sometimes have questions. Families may wonder where to get help. There are many programs in Michigan. Most are free. Many are run by parents who want to share information. This pamphlet tells about some of the resources available to families who have children with special needs. Your family might benefit from these services now or in the future.



## Family Support

**The Birth Defects Follow-up Program** at the Michigan Department of Community Health (MDCH) can help with referrals for support and services. The program publishes a resource book called "A Guide to Michigan Genetic Support Groups and Organizations." Parent consultants are also available to help answer questions about finding the right services for your child. To speak with a parent or get a copy of the guide, call (517) 335-8887 or e-mail [BDRFollowup@michigan.gov](mailto:BDRFollowup@michigan.gov)

Families of children with all types of special needs share information and support in the **Family Support Network of Michigan**. To contact the network, call the Children's Special Health Care Services (CSHCS) Family Phone Line at 1-800-359-3722.

**Family Support Services** are offered through your local community mental health agency. Case management can help you arrange services for your child. Behavior intervention, family skills development, and respite care services are also available. Through respite care, families get a short break from caring for a child with special needs. To apply for family support services, call your local **Community Mental Health Services Board (CMHSB)** listed in the business section or yellow pages. If you need help finding the telephone number, call (517) 335-8216.

The **Family Information Exchange (FIE)** is a parent-staffed project serving families of young children with special needs. FIE gives families information they want and helps them find support through other families. Call 1-800-292-7851 for more information or see [www.arcmi.org/](http://www.arcmi.org/)

**Parent HELpline** is a service of Gateway Community Services, funded by the Family Independence Agency. It is available to anyone who needs help right away. The HELpline is open 24 hours a day, seven days a week. Trained counselors provide crisis counseling, support and information. The free, confidential number is 1-800-942-HELP.



The **Parent Empowerment Project** serves families caring for children who are medically fragile or technology-dependent. Parent advocates can provide information and informal support. A related project, **Resources Unlimited Dedicated to You (RUDY)** provides information on medical equipment, resources and a supply exchange for caregivers of children with special needs. Call 1-800-262-0650, or see [www.for-rudy.com/](http://www.for-rudy.com/)

**Project PERFORM** is a support and resource center for families of children with disabilities. The project has a lending library of books and videotapes. It provides free information packets on selected topics. Parents oversee the center and answer calls at 1-800-552-4821. For information see the website [wash.k12.mi.us/~perform/](http://wash.k12.mi.us/~perform/)

## Special Health Care

Your local health department can provide information about **Children's Special Health Care Services (CSHCS)**. CSHCS helps to coordinate and pay for hospital and outpatient medical specialty care. Help may also be available for travel expenses related to a child's medical care. More than 2,000 diagnoses are eligible for coverage. For more information about CSHCS call 1-800-359-3722.

Children with developmental disabilities who reside with their birth or adoptive parents and are in need of intensive community living supports and/or private duty nursing services may be eligible for the **Children's Waiver Program**. Contact your local Community Mental Health Services Board (CMHSB) directly for more information. If you need the telephone number, call (517) 335-8216.

## Special Products

Advances in technology and new products help many children with special needs. **Michigan's Assistive Technology Resource (MATR)** has product information from more than 3,000 companies. Staff can help you find adaptive devices, special toys, clothing, equipment, and much more. Call 1-800-274-7426, or see [www.matr.org/](http://www.matr.org/)

## Early Intervention

One of the most important support systems for young children with special needs is called **Early On® Michigan**. It provides services for eligible children from birth to age three and their families regardless of income. The services may include:

- family training (skill building)
- counseling (family, group or individual)
- home visits
- special instruction (teaching)
- speech pathology
- audiology
- occupational therapy
- physical therapy
- psychological services
- service coordination
- diagnostic medical services
- early identification
- screening
- assessment services
- health services
- nursing services
- social work services
- vision services
- assistive technology devices and services
- nutritional counseling
- transportation

For more information, call 1-800-EARLY-ON (1-800-327-5966) voice and TDD.

The **Early On Parent Leadership Program** offers free leadership training for parents who want to get involved in policy and program activities. Call 1-800-292-7851 for more information.





## Special Education

Special education may help children who have physical, emotional, or mental conditions that prevent them from keeping up with others their age. Many services are offered free of charge by your public school system. **Project Find** helps to arrange a free evaluation through the local school district for any child who might need special education. For more information, call 1-800-252-0052.

## Financial Support

State and federal programs provide financial support to many families. Eligibility is usually based on the child's diagnosis and family income.

**Supplemental Security Income (SSI)** is a federal program that provides monthly payments and enables state Medicaid coverage for children with severe mental, emotional and physical disabilities. The family income must meet certain guidelines. To find out more, call the Social Security Administration at 1-800-772-1213.

The **Family Support Subsidy Program** provides monthly payments to some families whose child is severely mentally or multiply impaired, or autistic impaired as determined by the public school system. To apply for the **Family Support Subsidy Program**, call your local Community Mental Health Services Board (CMHSB). If you need the number, call (517) 335-8216.

The **Children with Special Needs Fund** provides funds for equipment such as therapeutic tricycles or wheelchair ramps when there is no other source of payment. Families with a child enrolled or medically eligible to enroll in Children's Special Health Care Services (CSHCS) may apply at their local health department or by calling 1-800-359-3722 or (517) 241-7420.

## Genetic Counseling

Genetics clinics offer evaluation and counseling. The clinic visit may provide information about a child's diagnosis, what to expect in the future, and whether the same condition could affect other people in the family. The **Hereditary Disorders Program** coordinates a network of genetics clinics in Michigan. Call (517) 335-8887 for more information.

## National Organizations

Information about many different conditions, even rare ones, is available from national support organizations and information centers.

To find out if there is a national group that deals with your child's diagnosis, call the **Genetic Alliance** at 1-800-336-GENE (336-4363), or see [www.geneticalliance.org/](http://www.geneticalliance.org/)

The **MUMS: National Parent-to-Parent Network** connects families of children who have a rare diagnosis. Call 1-877-336-5333, or see [www.netnet.net/mums/](http://www.netnet.net/mums/)

The **National Information Center for Children and Youth with Disabilities (NICHCY)** is a clearinghouse that offers information, referral, and free publications to families of children with special health needs. Call 1-800-695-0285, or see [www.nichcy.org/](http://www.nichcy.org/)

The **National Organization for Rare Disorders (NORD)** is dedicated to helping people with rare diseases that affect only a small number of people. Call 1-800-999-6673, or see [www.rarediseases.org/](http://www.rarediseases.org/) to access this information clearinghouse.

The **Fathers Network** celebrates and supports fathers and families raising children with special health care needs and developmental disabilities. For more information call (425) 747-4004 (x218), or see [www.fathersnetwork.org/](http://www.fathersnetwork.org/)